Genetic Counseling Resources

Associated with Comprehensive Sickle Cell & Hemoglobinopathy Centers

Children's Hospital and Medical Center
Odessa Brown Children's Clinic
2101 E. Yesler Way
Seattle, WA 98122
Message: (206) 987-7290
Appointment: (206) 987-7232

Columbia Health Center
4400 - 37th South
Seattle, WA 98118
Phone: (206) 296-4650

Mary Bridge Children's Hospital & Health Center
P.O. Box 5299
Tacoma, WA 98415-0299
Phone: (253) 403-3476

Prenatal Genetics Clinics
(For pregnant women only)

Evergreen Hospital
Maternal-Fetal Medicine
12040 NE 128th Street
Kirkland, WA 98034
Phone: (425) 899-2200

Perinatal Medicine
Swedish Medical Center
747 Broadway
Seattle, WA 98122-4307
Phone: (206) 386-2101

Prenatal Genetics and Fetal Therapy
University of Washington
Box 356159
Seattle, WA 98195
Phone: (206) 598-8130

Obstetrix Medical Group of Washington, Inc. P.S.
314 Martin Luther King Jr. Way, Suite 402
Tacoma, WA 98405
Phone: (253) 552-1037

Obstetrix Eastside Maternal Fetal Medicine
1135 116th Ave. NE, Ste. 320
Bellevue, WA 98004

General Genetics Clinics

Group Health Cooperative
Group Health University Center
4225 Roosevelt Way NE
Seattle, WA 98105
Phone: (206) 634-4036
Services limited to Group Health members

University of Washington Medical Center
Medical Genetics, Box 357720
1959 NE Pacific Street
Seattle, WA 98195-7720
Phone: (206) 616-2135

Inland Northwest Genetics Clinic
2607 Southeast Blvd #A100
Spokane, WA 99223
Phone: (509) 535-2278

Madigan Army Medical Center
Developmental Pediatrics
Tacoma, WA 98431-5000
Phone: (253) 968-2310
Services limited to Armed Services personnel and their dependents

Children's Hospital and Regional Medical Center
P.O. Box 5371, 4H-4
4800 Sand Point Way NE
Seattle, WA 98105
Phone: (206) 987-2665

University of Washington Biochemical Genetics
Box 356320
Seattle, WA 98195-6320
Phone: (206) 616-1840
Fax: (206) 543-3379

Blue Mountain Genetic Counseling
St. Mary Medical Center
P.O. Box 1477
Walla Walla, WA 99362
Phone: (509) 525-1302

Central Washington Genetics Program
Yakima Valley Memorial Hospital
2811 Tieton Drive
Yakima, WA 98902
Phone: (509) 575-8160
&
Genetics Program
Central Washington Hospital
1201 South Miller
Wenatchee, WA 98801
Phone: (509) 667-3350

Washington State Department of Health
DOH Pub 304-002
Revised February 2005

Alpha Thalassemia

Information for parents about hemoglobin Bart's and alpha thalassemia

What is hemoglobin?

Hemoglobin is the part of blood that carries oxygen to all parts of the body. Genes that we inherit from our parents determine what type of and how much hemoglobin we have.

What is alpha thalassemia?

Hemoglobin is made up of many different parts, including alpha globin. Alpha globin is produced by four genes and when any of those genes are not working properly the body makes less hemoglobin. This is called alpha thalassemia and occurs in four different forms, depending on the number of genes not working. One form of alpha thalassemia cannot turn into another kind. Your child will have that form for his or her entire life.

Why was my child screened for alpha thalassemia?

The Newborn Screening Program screens all infants born in Washington State for certain disorders, including hemoglobin disorders. A small amount of blood was collected from your infant's heel and sent to the State Laboratory for testing. That testing found a higher than normal level of hemoglobin Bart's, a protein that is made when alpha globin genes are not working properly.

What happens when one gene for alpha globin is not working?

A person who has one of the four alpha globin genes not working is called a silent carrier. This form of alpha thalassemia does not cause any major changes in the hemoglobin or any health problems.

What happens when two genes for alpha globin are not working?

A person who has two of the four alpha globin genes not working has alpha thalassemia trait. This form of alpha thalassemia causes only small changes in the hemoglobin and does not cause any health problems.

If one or two non-working genes for alpha globin do not cause any health problems, why do I need to know that my child has alpha thalassemia?

Although one or two non-working alpha globin genes do not cause any health problems, you and your baby's doctor should know that it can cause a mild anemia (low number of red blood cells). It is also important to know about your child's alpha thalassemia status because future children in your family, or other family members, may be at risk for more serious forms of alpha thalassemia, which are described on the next page. Also, people with the silent carrier form or alpha thalassemia trait can pass the gene(s) to their children.

What happens when three or four genes for alpha globin are not working?

If a person has three non-working genes, it will result in hemoglobin H disease. Hemoglobin H disease can sometimes cause serious health problems due to moderate or marked anemia and should be followed regularly by a doctor. People with four non-working genes are unable to produce the hemoglobin needed to live. This is called alpha thalassemia major. This is not what your child has. This form causes death in the affected individual before or soon after birth. If your doctor or genetic counselor feels that you are at risk for having a baby with either of these forms of alpha thalassemia, they will provide you with more information.

What do I do now?

Your baby's doctor may do more testing on your baby to clarify which form of alpha thalassemia your baby has (whether one or two genes are not working). This will involve drawing a small amount of blood from your baby. It is also recommended that you and your partner have testing done to determine your hemoglobin status. This would provide information on your chances of having a future child with a more serious form of alpha thalassemia. To have this testing done, talk to your health care provider or one of the genetic counselors listed on the back of this pamphlet. You may also want to share this information with the rest of your family. They may be interested in finding out their hemoglobin status as well.

What can I do if I have more questions?

If you have more questions, you can talk to your child's health care provider or you can contact the Newborn Screening Program using the information below.

Newborn Screening Program
1610 NE 150th Street
Shoreline, WA 98155
Phone: (206) 418-5410
Email: NBS.Prog@doh.wa.gov
Internet: www.doh.wa.gov/nbs